



Informing Children about their Sibling's Diagnosis of ASD

For typically developing (TD) children, living with a sibling with a disability such as autism spectrum disorder (ASD) can affect their lives in many ways. A number of factors such as sex, age, birth order, severity of disability, family size and socioeconomic status may influence their relationships within the family. One issue complicating the relationship between siblings and particularly relevant to ASD is when one child is having difficulties gaining social skills to develop age appropriate relationships. TD children may suffer high levels of stress and feel confusion and resentment toward their sibling's unusual behaviours such as temper tantrums. TD children may cope better with these behaviours and the relationship between siblings may be of better quality if the TD child has information about ASD.

Previous research has found that, compared to TD children whose siblings had physical disabilities, TD children whose siblings had ASD needed to be older to understand the concepts associated with ASD. It is important that children have a good understanding of ASD to be able to offer support to their sibling. This is because ASD is a lifelong disability, and TD siblings are often highly involved with the child with ASD.

The Study

The aim of this study was to investigate the way in which parents currently inform TD children about their sibling's diagnosis of ASD. Seventy seven families from Japan took part in the study, who, between them had 108 TD children. To take part in

the study, the families filled in a questionnaire.

Informing Typically Developing Siblings about ASD

At the time of the study, 72 of the 108 (67%) TD children had been told of the ASD diagnosis. The average age at which the children were told was around nine years, although this ranged between two years and 22 years. Most of the children were told between the ages of six and 12 years.

Parents were more likely to tell their TD child about the ASD if the TD child was older than the child with ASD and if the age difference between the children was more than two years.

TD children tended to be told earlier if they were female, younger than their sibling with ASD, and when the age between siblings was less than two years. When the child diagnosed with ASD was high functioning (IQ over 70), the TD siblings were told less often and if told, this tended to occur at an older age.

Most commonly, it was the mother who told the TD child about the ASD (67%), followed by both parents (31%).



Parental Explanations

When the TD children were told about the ASD diagnosis of their sibling, other information was provided at the same time. The table below shows the type of information given, an example and the percentage of cases it was given in¹:

Information	Example	%
Symptoms and difficulties	He/she can't talk	62
Having a disability	He/she has disability called autism	29
Cause of disability	Autism is a disease of brain	28
Reason for special education	He/she needs to study slowly	11
How to support	Please help him/her	6
Feelings of child with ASD	He/she means no harm	5
Positive aspects of ASD	He/she is honest	5
Tips for dealing with ASD	Please speak to him/her slowly	3
Prognosis	Autism cannot be cured	3
Similarity	Everybody has difficulties	2

Questions of Typically Developing Children

In 62% of the families, parents reported that the TD child had asked questions about the child diagnosed with ASD. The table below shows the type of question, an example and the percentage of cases it was asked in²:

Type of Question	Example	%
Communication problems	Why can't he/she talk?	25
Difference in parent's attitude	Why are you kind only to him/her?	19
Odd behaviours	Why does he/she jump so often?	18
Education differences	Why does he/she go to a different school?	12
Developmental delay	Why does he/she need help to do this?	9
Difference from others	Why does he/she behave differently?	9
Need for therapy/treatment	Why does he/she go to this centre?	7
Obsessive behaviours	Why is he/she obsessive about this?	2

Responses of Typically Developing Children

Most TD children (78%) had guessed the diagnosis or noticed that there was something different about their sibling before they were told about the diagnosis of ASD. When they were told about the diagnosis, half of the children (45%) showed 'no particular' reaction. Some of the children (14%) were more accepting than their parents expected, some (14%) showed understanding, and some were interested in learning more (7%). Seemingly few children were sad (11%), surprised (3%) or did not understand (2%).

Conclusion

Overall, two thirds of TD children in the study had been told of their sibling's diagnosis of ASD. Typically, children were told between the ages of 9 and 12. If and

¹ and ² The percentages in the table do not add to 100% as more than one piece of information was given in many cases.



when the children were told depended on factors such as age, sex, birth order, and the severity of the ASD. Most children had an idea that something was different about their sibling before they were told, and when they were told, most children reacted positively or showed no real reaction.

Reference

Tanaka, K., Uchiyama, T. & Endo, F. (2011). Informing children about their sibling's diagnosis of autism spectrum disorder: An initial investigation into current practices. *Research in Autism Spectrum Disorders, 5*, 1421-1429.

